

South Dakota

Children's
Special
Health
Services



Survey Report

2005 - 2006

Overview of the State

South Dakota is one of the least densely populated states in the nation with 775,933 people living within its 75,806 square miles – an average population density of 10.2 people per square mile (2005 Census Estimate). Over half (34) of the state's 66 counties are classified as frontier (population density of less than six persons per square mile) while 29 are considered rural (population density of six or more persons per square mile but no population centers of 50,000 or more). Three counties are classified as urban (have a population center of 50,000 or more). Of the state's total population, 89 percent are white (of which 98 percent are white alone, not Hispanic or Latino), 9 percent are Native American and the remaining 2 percent are classified as some other race or more than one race.

According to the 2004 Current Population Survey, 13.4 percent of South Dakotans live below 100 percent of the federal poverty level (FPL) compared to 12.7 percent for the nation. The percent of South Dakotans living under 200 percent of the FPL was 31.1 compared to 31.2 percent for the nation. When looking at poverty levels for counties on Indian reservations in the state these numbers are significantly higher.

Methods

The South Dakota Department of Health conducted a survey of parents of children with special healthcare needs (CSHCN) in conjunction with the South Dakota Parent Connection, the state's Parent Training and Information (PTI) Center. Responses to the survey were accepted from December 2005 through March 2006. Questions were asked to gather data pertaining to prevalent conditions and disparities in delivering services to the resident CSHCN population. Mailing lists of parents/households were obtained from the South Dakota Parent Connection and the South Dakota Children's Special Health Services program. A total of 1,896 surveys were sent out. Of the surveys sent out, 80 were not deliverable as addressed, 52 of these were not resent because they had moved out of state or no forwarding address was available. A total of 477 of the 1844 were completed and returned by deadline of which 474 were entered into the database, indicating 447 health care conditions. Three of the completed returns were not entered because they indicated they had moved out of state or that services were no longer needed. This yields a return rate of approximately 26 percent. A copy of the survey can be found in the Appendix of this report.

Data collected from the previous survey, 2004-2005, are included in this report for comparative purposes only, trends should not be established using only two years of data. One can only establish if the answers to the question are higher or lower than the previous survey. Responses to the 2004-2005 survey were accepted from November 2004 through February 2005. Over 1,800 surveys were sent out although the actual response rate was not calculated due to the high frequency of undeliverable addresses. The 642 completed surveys returned provided information on 927 children indicating 1,439 health care conditions. Information for up to three children could be reported on each survey. A copy of the survey used is included in the Appendix of this report.

2006 Survey Results

1. County where you live?

Eight of South Dakota's 66 counties; Corson, Deuel, Harding, Jerauld, McCook, Mellette, Miner and Moody County had no respondents represented in the survey. The number of responses per county ranged from a low of 0 to a high of 83. The county with the most responses was Brown with 83. Nineteen percent (11 of 58) of the counties reporting had over 9 respondents each.

2. What is the child's age?

Answers ranged from 0 through 33 years. The median age was 8 years with the average age being 9 years; the mode was 2 years of age. There were 9 individuals listed as over 21 years of age.

3. List your child's condition that requires more than the usual medical care, mental health, or educational services that has lasted or is expected to last 12 months or longer.

Of the 474 children for which surveys were received, 447 had conditions listed in response to this question. Of the 447 surveys indicating conditions, 306 or 68.5 percent indicated one condition, 81 or 18.1 percent indicated two conditions, 32 (7.2 percent) indicated three and 28 (6.3 percent) indicated more than three health care conditions. The groups containing 10 or more entries in the categorical conditions in ascending order are as follows. The most reported health care conditions were pulmonary related conditions accounting for 37.4 percent (167) of the 447 responses, 74 or 16.6 percent were endocrine related, 69 or 15.4 percent were neurology related, 47 or 10.5 percent were cardiac related, 36 or 8.1 percent were genetics related and 20 or 4.5 percent were related to physical medicine and rehabilitation, see page 3 for a full list.

| Multiple responses to the question: 3. List your child's condition that requires more than the usual medical care, mental health, or educational services that has lasted or is expected to last 12 months or longer. | | | |
|--|---------------|---------------------------|---------------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total Response | 474 | 100.0% | |
| Not Answered/Blank | 27 | 6.1% | |
| Non-Blank Question Responses | 447 | 94.3% | 100.0% |
| One Health Care Condition Indicated | 306 | 64.6% | 68.5% |
| Two Health Care Conditions Indicated | 81 | 17.1% | 18.1% |
| Three Health Care Conditions Indicated | 32 | 6.8% | 7.2% |
| More Than Three Health Care Conditions Indicated | 28 | 5.9% | 6.3% |

Source: South Dakota Department of Health

| 3. List your child's condition that requires more than the usual medical care, mental health, or educational services that has lasted or is expected to last 12 months or longer. | | |
|---|--------|---------|
| Non-Blank Question Responses | Number | Percent |
| Total | 447 | 100.0% |
| Pulmonary | 167 | 37.4% |
| Endocrine | 74 | 16.6% |
| Neurology | 69 | 15.4% |
| Cardiac | 47 | 10.5% |
| Genetics | 36 | 8.1% |
| Physical Medicine and Rehabilitation | 20 | 4.5% |
| Gastric | 9 | 2.0% |
| Emotional Health | 8 | 1.8% |
| Metabolic | 7 | 1.6% |
| Visual Impairment | 5 | 1.1% |
| Renal | 2 | 0.4% |
| Hearing Impairment | 1 | 0.2% |
| Hematology/Oncology | 1 | 0.2% |
| Other conditions | 1 | 0.2% |

Source: South Dakota Department of Health

4. How do you pay for your child's health care services? (Check all that apply)

- ☐ Privately purchased insurance
- ☐ Employer group insurance
- ☐ Medicaid/CHIP
- ☐ Indian Health Services
- ☐ Tri-Care (military coverage)
- ☐ Out of pocket/self pay

Payment sources were indicated for 473 children. One payment source was indicated for 275 or 58.1 percent and 185 or 39.1 percent indicated two sources. Only 13 or 2.8 percent indicated more than two payment sources. Multiple payment sources were permitted for this question with 684 responses received from the 473 surveys completing this question. There were 228 or 33.3 percent who indicated employer group insurance as a payment source, this being the most common answer. Medicaid/CHIP was the second most frequently indicated category with 212 or 31.0 percent of the responses, and out of pocket/self pay was the third most common answer with 137 or 20.0 percent. Private insurance was the fourth most indicated source with 83 or 12.1 percent of the responses, and a combination of Indian Health Service and Tri-Care comprised only 3.6 percent of the responses. One survey returned did not answer this question.

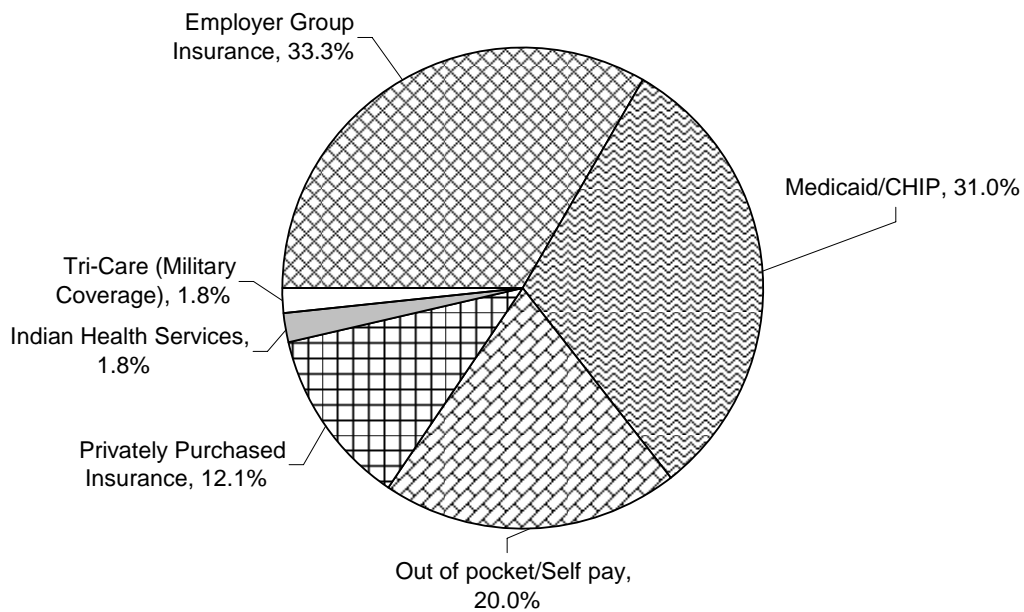
| Multiple responses to the question: 4. How do you pay for your child's health care services? | | | |
|--|--------|--------------------|--------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total Surveys Returned | 474 | 100.0% | |
| Not Answered/Blank | 1 | 0.2% | |
| Non-Blank Answers Received | 473 | 99.8% | 100.0% |
| One Pay Source Indicated | 275 | 58.0% | 58.1% |
| Two Pay Sources Indicated | 185 | 39.0% | 39.1% |
| Three Pay Sources Indicated | 13 | 2.7% | 2.8% |
| Four Pay Sources Indicated | 0 | 0.0% | 0.0% |

Source: South Dakota Department of Health

| 4. How do you pay for your child's health care services? | | |
|--|--------|---------|
| Non-Blank Question Responses | Number | Percent |
| Total | 684 | 100.0% |
| Employer Group Insurance | 228 | 33.3% |
| Medicaid/CHIP | 212 | 31.0% |
| Out of Pocket/Self Pay | 137 | 20.0% |
| Privately Purchased Insurance | 83 | 12.1% |
| Indian Health Services | 12 | 1.8% |
| Tri-Care (Military Coverage) | 12 | 1.8% |

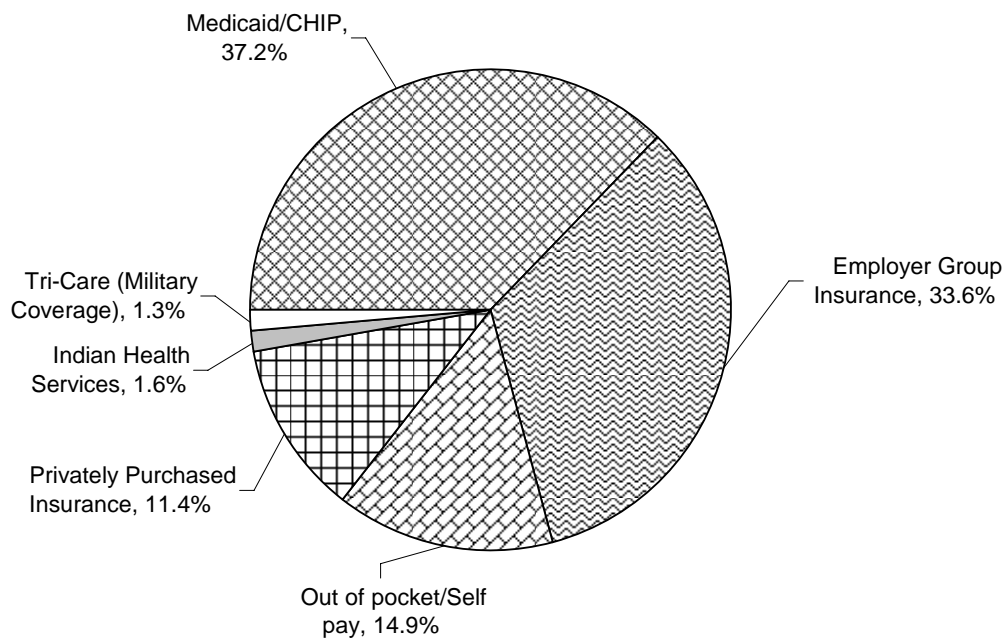
Source: South Dakota Department of Health

How do you pay for your child's health care services? 2006



Source: South Dakota Department of Health

How do you pay for your child's health care services? 2005



Source: South Dakota Department of Health

5a. Do you feel you have adequate health insurance? (Check one answer)

☐ Yes
☐ No

5b. If no, why? (Check all that apply)

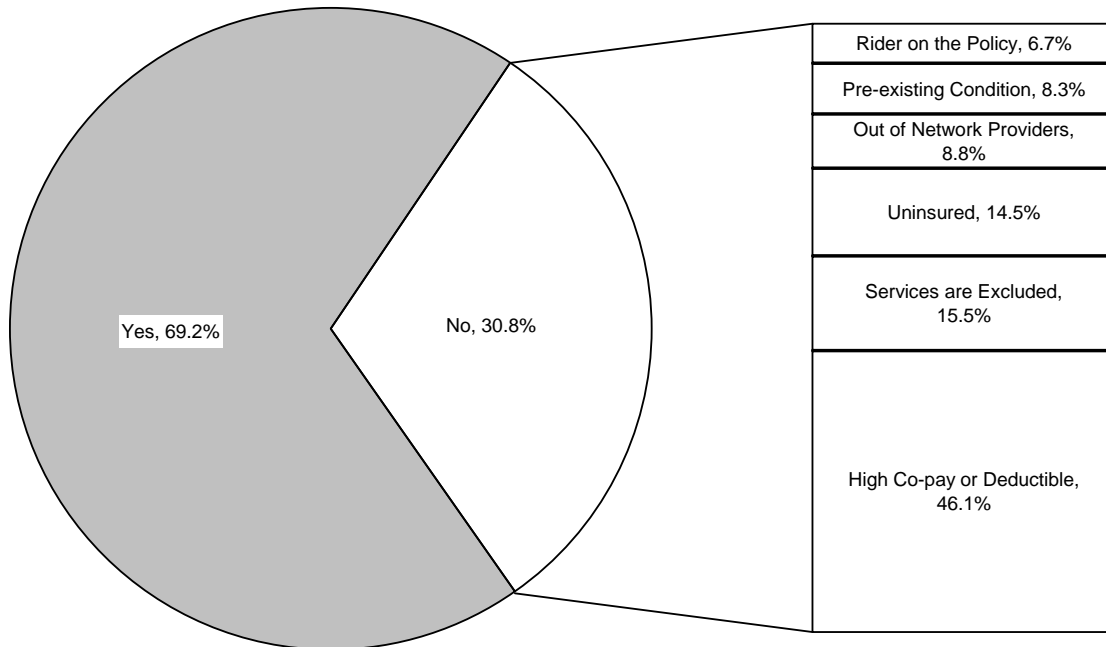
☐ High co-pay or deductible
☐ Rider on the policy
☐ Pre-existing condition
☐ Out of network providers
☐ Services are excluded
☐ Uninsured

Of the 474 individuals on whom data was returned, 471 answered this question. Of those answering the question 326 or 69.2 percent answered “Yes” and 145 or 30.8 percent indicated “No”. Those answering no were asked “If No Why?”, of which only 142 responded. High co-pay and high deductibles were the most common reasons cited, with 89 or 46.1 percent of the responses, while 35 or 24.6 percent of the respondents listed multiple reasons. The second and third reasons most frequently indicated were services excluded and uninsured. Three surveys did not answer the question and three answered both yes and no. Questions answered with yes and no were considered as no answers in the analysis.

| 5. Do you feel you have adequate health insurance? | | | |
|---|---------------|---------------------------|---------------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total | 474 | 100.0% | |
| Not Answered/Blank | 3 | 0.6% | |
| Non-Blank Answers Received | 471 | 99.4% | 100.0% |
| Yes | 326 | 68.8% | 69.2% |
| No | 145 | 30.6% | 30.8% |
| If No Why? (Check all that apply) | | | |
| Multiple Responses to “No” Answers | 145 | 100.0% | |
| Not Answered/Blank | 3 | 2.1% | |
| Non-Blank Answers Received | 142 | 97.9% | 100.0% |
| One Reason Indicated | 104 | 71.7% | 73.2% |
| Two Reasons Indicated | 28 | 19.3% | 19.7% |
| Three Reasons Indicated | 4 | 2.8% | 2.8% |
| Four Reasons Indicated | 3 | 2.1% | 2.1% |
| Non-Blank Responses to “No” Answers | 193 | | 100.0% |
| High Co-Pay or Deductible | 89 | | 46.1% |
| Rider on the Policy | 13 | | 6.7% |
| Pre-Existing Condition | 16 | | 8.3% |
| Out of Network Providers | 17 | | 8.8% |
| Services are Excluded | 30 | | 15.5% |
| Uninsured | 28 | | 14.5% |

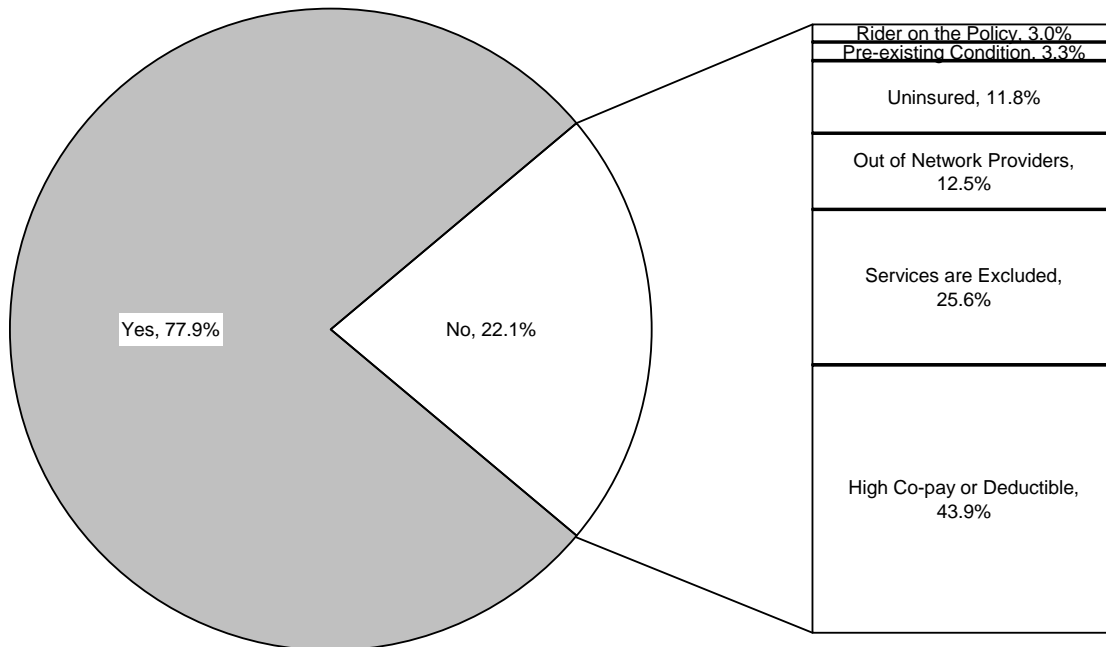
Source: South Dakota Department of Health

Do you feel you have adequate health insurance? **2006**



Source: South Dakota Department of Health

Do you feel you have adequate health insurance? **2005**



Source: South Dakota Department of Health

6. Types of medical care/treatment needed?

| Service | Miles from Home | Visits per Year |
|---|--|--|
| Care/Treatment | The number of miles traveled (one way) for each service listed | The number of visits needed annually for each service listed |
| Prescription Drugs (Pharmacy) | | |
| Therapy(Physical, Occupational, Speech) | | |
| Routine Lab Tests | | |
| Primary Care Physician Visits | | |
| Specialty Care Physician Visits | | |
| Special Equipment | | |
| Counseling | | |
| Other (List) _____ | | |

When asked about the distance from selected healthcare and/or treatment centers 38.9 percent indicated less than 10 miles. Slightly less than three-quarters (73.5 percent) were less than 50 miles from treatment. The number of respondents indicating they were within 100 miles of treatment was 87.2 percent. The number of visits needed per year to the same healthcare and/or selected treatments indicated that 82.3 percent needed no more than 12 treatments per year. The number needing 24 visits or less was 89.5 percent, indicating that fewer than 10.5 percent average more than two treatments per month. Of the returned surveys, 37 were left blank in the "Miles from Home" column and 43 were left blank in the "Visits per Year" columns of this question. There were 19 surveys with no entries in both the "Miles from Home" or the "Visits per Year" column of this question.

| 6. Types of medical care/treatment needed? | | | | | | | | | |
|--|--------|-------|-------|-------|-------|-------|-------|---------|------|
| Miles from Home | | | | | | | | | |
| | Total | <10 | 10-19 | 20-29 | 30-39 | 40-49 | 50-99 | 100-199 | 200+ |
| Total Treatments | 1523 | 592 | 246 | 132 | 84 | 66 | 208 | 86 | 109 |
| Percent | 100.0% | 38.9% | 16.2% | 8.7% | 5.5% | 4.3% | 13.7% | 5.6% | 7.2% |
| Prescription Drugs (Pharmacy) | 329 | 180 | 60 | 35 | 15 | 13 | 20 | 5 | 1 |
| Therapy | 92 | 47 | 19 | 5 | 4 | 3 | 9 | 1 | 4 |
| Routine Lab Tests | 219 | 92 | 34 | 22 | 17 | 9 | 30 | 8 | 7 |
| Primary Care Physician Visits | 343 | 147 | 72 | 32 | 21 | 18 | 40 | 10 | 3 |
| Specialist Care Physician Visits | 383 | 89 | 36 | 23 | 17 | 16 | 84 | 47 | 71 |
| Special Equipment | 89 | 19 | 16 | 7 | 3 | 4 | 16 | 12 | 12 |
| Counseling | 42 | 16 | 5 | 5 | 5 | 3 | 6 | 2 | 0 |
| Other (List) | 26 | 2 | 4 | 3 | 2 | 0 | 3 | 1 | 11 |
| Visits per Year | | | | | | | | | |
| | Total | <=12 | 13-24 | 25-36 | 37-48 | 49-72 | 73-96 | 97-120 | 120+ |
| Total Treatments - Visits | 1,426 | 1,173 | 102 | 30 | 19 | 44 | 1 | 20 | 37 |
| Percent | 100.0% | 82.3% | 7.2% | 2.1% | 1.3% | 3.1% | 0.1% | 1.4% | 2.6% |
| Prescription Drugs (Pharmacy) | 308 | 231 | 55 | 17 | 3 | 2 | 0 | 0 | 0 |
| Therapy | 120 | 18 | 5 | 3 | 9 | 31 | 1 | 18 | 35 |
| Routine Lab Tests | 200 | 192 | 6 | 1 | 1 | 0 | 0 | 0 | 0 |
| Primary Care Physician Visits | 285 | 264 | 17 | 4 | 0 | 0 | 0 | 0 | 0 |
| Specialist Care Physician Visits | 372 | 361 | 8 | 0 | 0 | 1 | 0 | 1 | 1 |
| Special Equipment | 71 | 67 | 3 | 0 | 0 | 0 | 0 | 0 | 1 |
| Counseling | 42 | 17 | 7 | 4 | 4 | 9 | 0 | 1 | 0 |
| Other (List) | 28 | 23 | 1 | 1 | 2 | 1 | 0 | 0 | 0 |

Source: South Dakota Department of Health

7a. As parents, are you satisfied with the involvement you have had with your child's health care team in making decisions about what care is provided to your child? (Check one answer)

☐ Yes
☐ No

7b. If no, why? (Check all that apply)

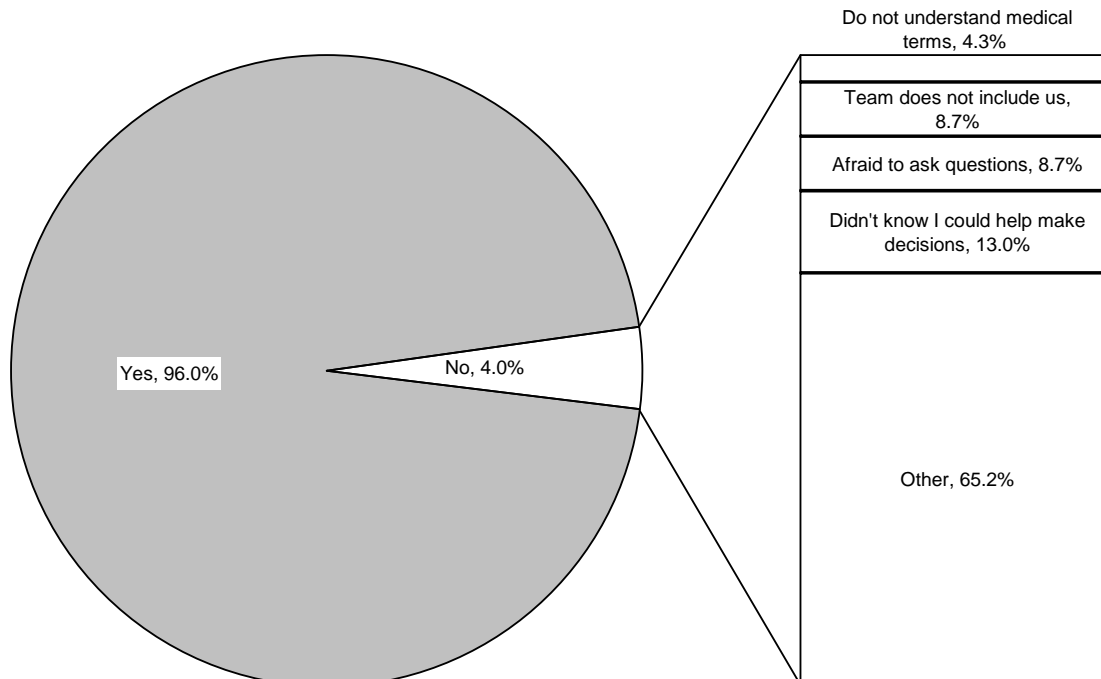
☐ Do not understand medical terms
☐ Team does not include us
☐ Afraid to ask questions
☐ Didn't know I could help make decisions
☐ Other reasons (List): _____

Ninety-six percent of those answering this question indicated they were satisfied with their involvement. Of the 474 surveys, 471 or 99.4 percent answered the question, three left the question blank.

| 7. As parents, have you been satisfied with the involvement you have had with involvement you have had with your child's health care team in making decisions about what care is provided to your child? | | | |
|---|---------------|---------------------------|---------------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total | 474 | 100.0% | |
| Not Answered/Blank | 3 | 0.6% | |
| Non-Blank Answers Received | 471 | 99.4% | 100.0% |
| Yes | 452 | 95.4% | 96.0% |
| No | 19 | 4.0% | 4.0% |
| If No Why? (Check all that apply) | | | |
| Multiple Responses to "No" Answers | 23 | 100.0% | |
| Not Answered/Blank | 0 | 0.0% | |
| Non-Blank Answers Received | 23 | 100.0% | 100.0% |
| One Reason Indicated | 17 | 73.9% | 73.9% |
| Two Reasons Indicated | 1 | 4.3% | 4.3% |
| Four Reasons Indicated | 1 | 4.3% | 4.3% |
| Non-Blank Responses to "No" Answers | 23 | | 100.0% |
| Do Not Understand Medical Terms | 1 | | 4.3% |
| Team Does Not Include Us | 2 | | 8.7% |
| Afraid to Ask Questions | 2 | | 8.7% |
| Didn't Know I Could Help Make Decisions | 3 | | 13.0% |
| Other Reasons (List): | 15 | | 65.2% |

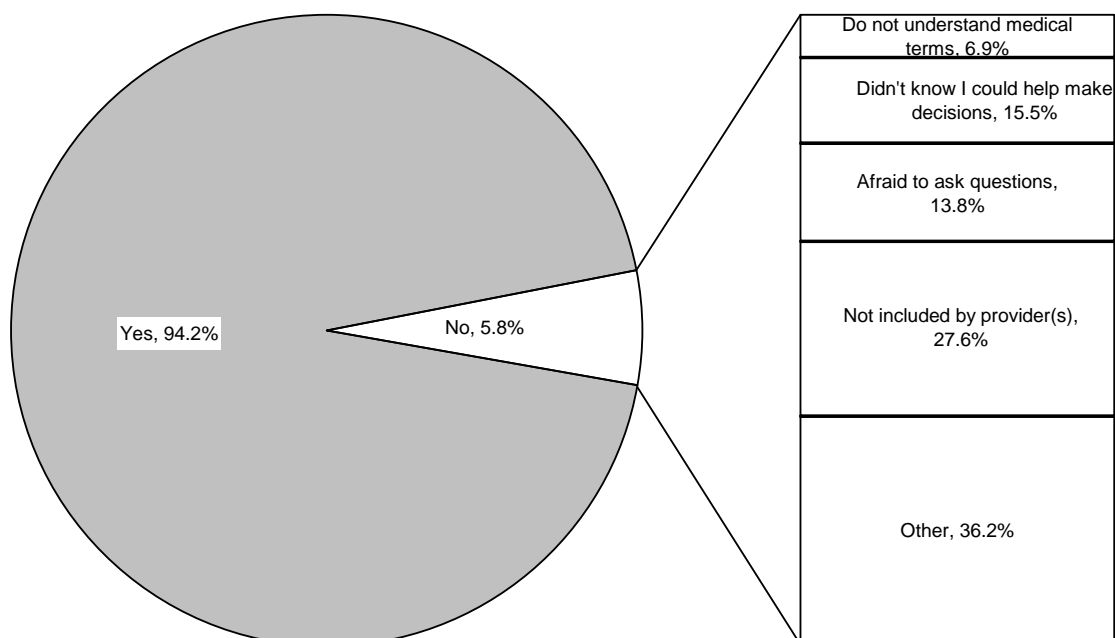
Source: South Dakota Department of Health

As parents, have you been satisfied with the involvement you have had with your child's health care team in making decisions about what care is provided to your child?
2006



Source: South Dakota Department of Health

As parents, have you been satisfied with the involvement you have had with your child's health care team in making decisions about what care is provided to your child?
2005



Source: South Dakota Department of Health

8. Does your child's primary doctor work with you to identify and access all the medical and non-medical services needed to help your child and family achieve their goals?

(Check one answer)

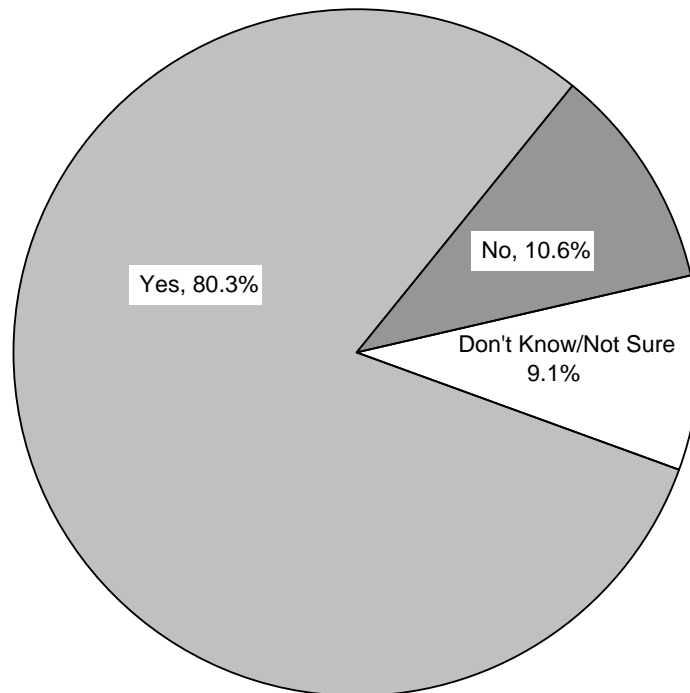
- ☐ Yes
☐ No
☐ Don't Know/Not Sure

There were 473 responses to this question. Responses included 380 or 80.3 percent "Yes", 50 or 10.6 percent "No", and 43 or 9.1 percent "Don't Know/Not Sure". One survey left the question blank.

| 8. Does your child's primary doctor work with you to identify and access all the medical and non-medical services needed to help your child and family achieve their goals? | | | |
|--|---------------|---------------------------|---------------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total Surveys Returned | 474 | 100.0% | |
| Not Answered/Blank | 1 | 0.2% | |
| Non-Blank Answers Received | 473 | 99.8% | 100.0% |
| Yes | 380 | 80.2% | 80.3% |
| No | 50 | 10.5% | 10.6% |
| Don't Know/Not Sure | 43 | 9.1% | 9.1% |

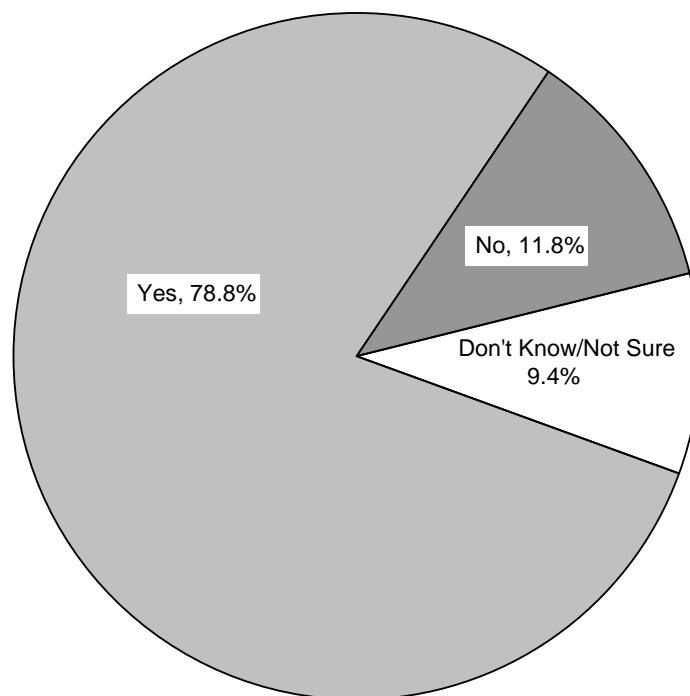
Source: South Dakota Department of Health

Does your child's primary doctor work with you to identify and access all the medical and non-medical services needed to help your child and family achieve their goals?
2006



Source: South Dakota Department of Health

Does your child's primary doctor work with you to identify and access all the medical and non-medical services needed to help your child and family achieve their goals?
2005



Source: South Dakota Department of Health

9. How would you rate the communication between your child's primary doctor and other health care providers about your child's care? (Check one answer)

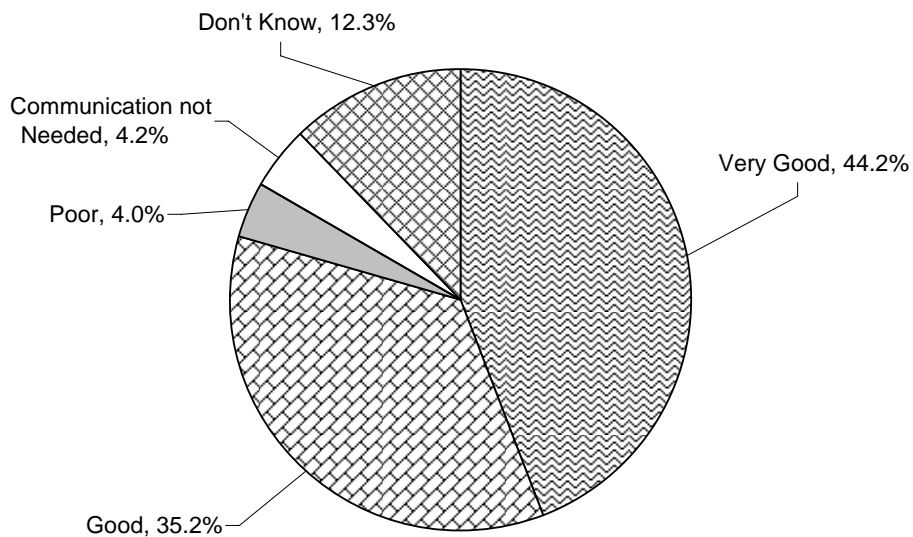
- ☐ Very good
☐ Good
☐ Poor
☐ Communication not needed
☐ Don't know/not sure

Of the 413 respondents with answers other than "Don't Know", the results indicate that 374 or 95.4 percent answered; "Very Good", "Good" or "Communications not Needed". The remaining 19 or 4.6 percent indicated feeling that the communications are poor. Three surveys left the question blank.

| 9. How would you rate the communication between your child's primary doctor and other health care providers about your child's care? | | | |
|---|---------------|---------------------------|---------------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total Surveys Returned | 474 | 100.0% | |
| Not Answered/Blank | 3 | 0.6% | |
| Non-Blank Answers Received | 471 | 99.4% | 100.0% |
| Very Good | 208 | 43.9% | 44.2% |
| Good | 166 | 35.0% | 35.2% |
| Poor | 19 | 4.0% | 4.0% |
| Communication Not Needed | 20 | 4.2% | 4.2% |
| Don't Know | 58 | 12.2% | 12.3% |

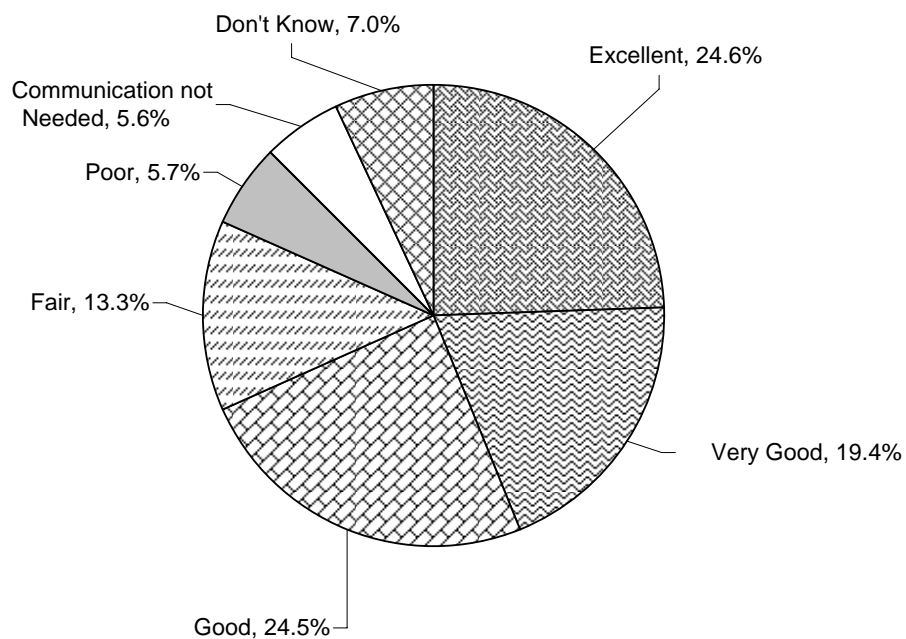
Source: South Dakota Department of Health

**How would you rate the communication between your child's primary doctor
and other health care providers about your child's care?
2006**



Source: South Dakota Department of Health

**How would you rate the communication between your child's primary doctor
and other health care providers about your child's care?
2005**



Source: South Dakota Department of Health

10. How would you rate the communication between your child's primary doctor and each of the following: (child's) school, early intervention program, child care providers, or vocational rehabilitation program?

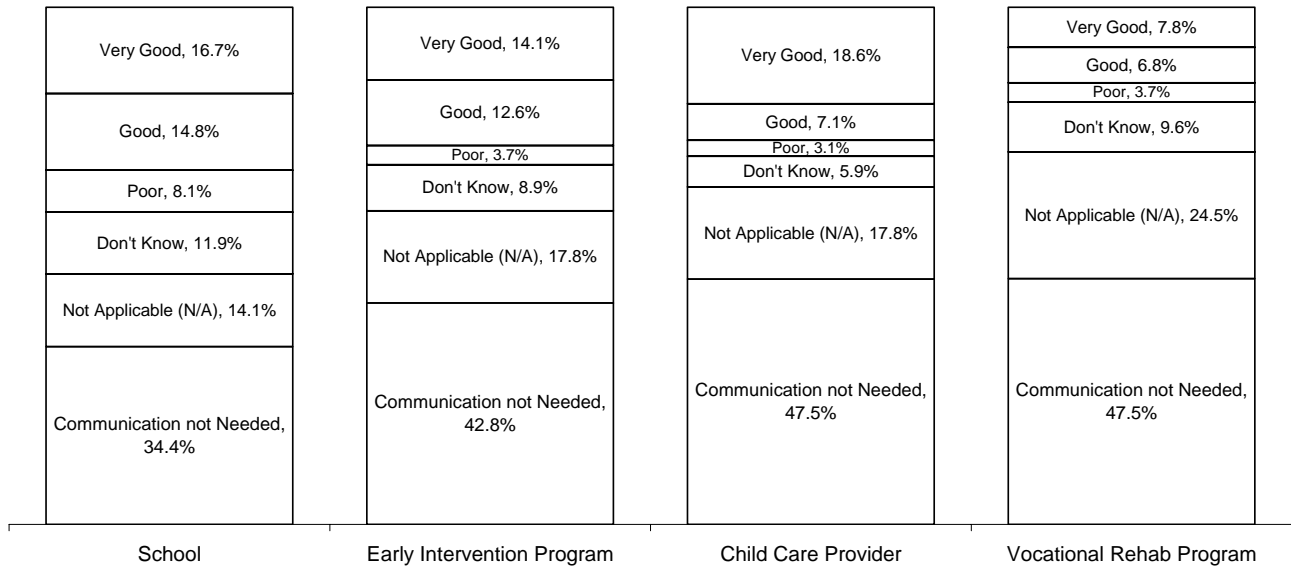
| Rating: | School | Early Intervention Program | Child Care Provider | Vocational Rehab Program |
|--------------------------|---------------|-----------------------------------|----------------------------|---------------------------------|
| Very Good | | | | |
| Good | | | | |
| Poor | | | | |
| Communication Not Needed | | | | |
| Don't Know/Not Sure | | | | |

The most common answer to this question was "Communication not Needed". Each of the four categories were not answered for every child included with this survey. "School" was the category generating the most responses (419), with the other three categories varying by less than 50 responses. The "Not Applicable (N/A)" category was added to the database due to this option being written in by respondents for this question.

| 10. How would you rate the communication between your child's primary doctor and each of the following: (child's) school, early intervention program, child care providers, or vocational rehabilitation program? | | | | | | | | |
|--|---------------|----------------|-----------------------------------|----------------|----------------------------|----------------|---------------------------------|----------------|
| | School | | Early Intervention Program | | Child Care Provider | | Vocational Rehab Program | |
| Responses | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Total | 419 | 100.0% | 348 | 100.0% | 354 | 100.0% | 322 | 100.0% |
| Very Good | 70 | 16.7% | 49 | 14.1% | 66 | 18.6% | 25 | 7.8% |
| Good | 62 | 14.8% | 44 | 12.6% | 25 | 7.1% | 22 | 6.8% |
| Poor | 34 | 8.1% | 13 | 3.7% | 11 | 3.1% | 12 | 3.7% |
| Communication Not Needed | 144 | 34.4% | 149 | 42.8% | 168 | 47.5% | 153 | 47.5% |
| Don't Know | 50 | 11.9% | 31 | 8.9% | 21 | 5.9% | 31 | 9.6% |
| Not Applicable (N/A) | 59 | 14.1% | 62 | 17.8% | 63 | 17.8% | 79 | 24.5% |

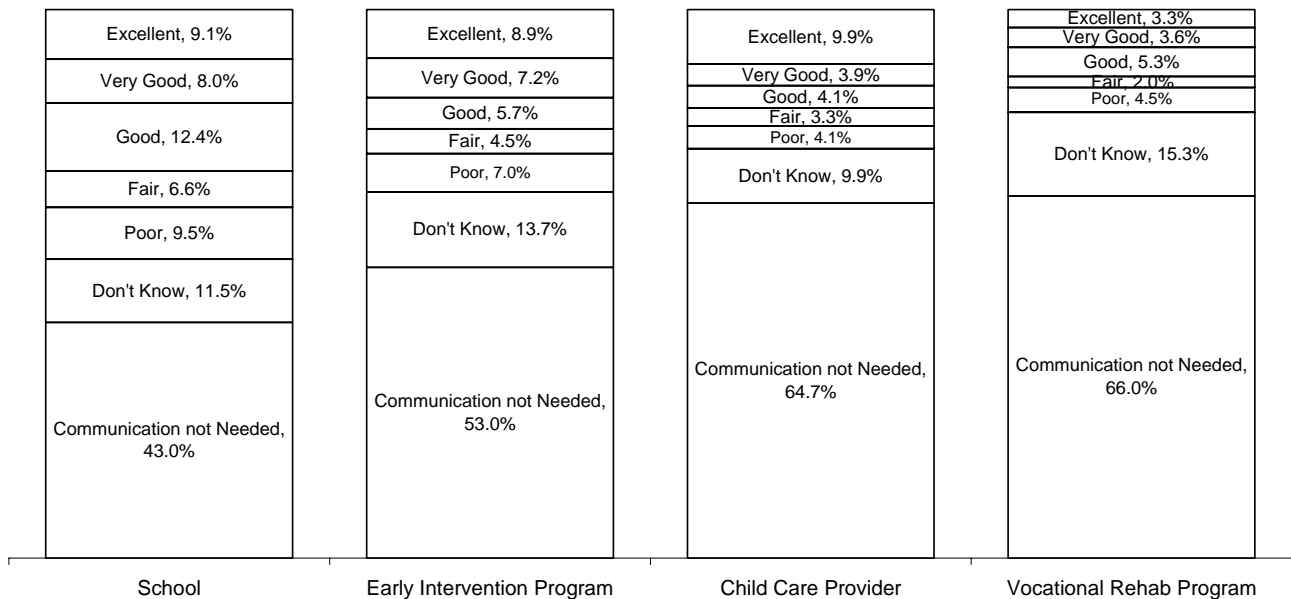
Source: South Dakota Department of Health

**How well do you think your child's primary doctor communicates with each of the following
2006**



Source: South Dakota Department of Health

**How well do you think your child's primary doctor communicates with each of the following
2005**



Source: South Dakota Department of Health

11. Do you feel the community-based services you use are organized and easy to use?

(Check one answer)

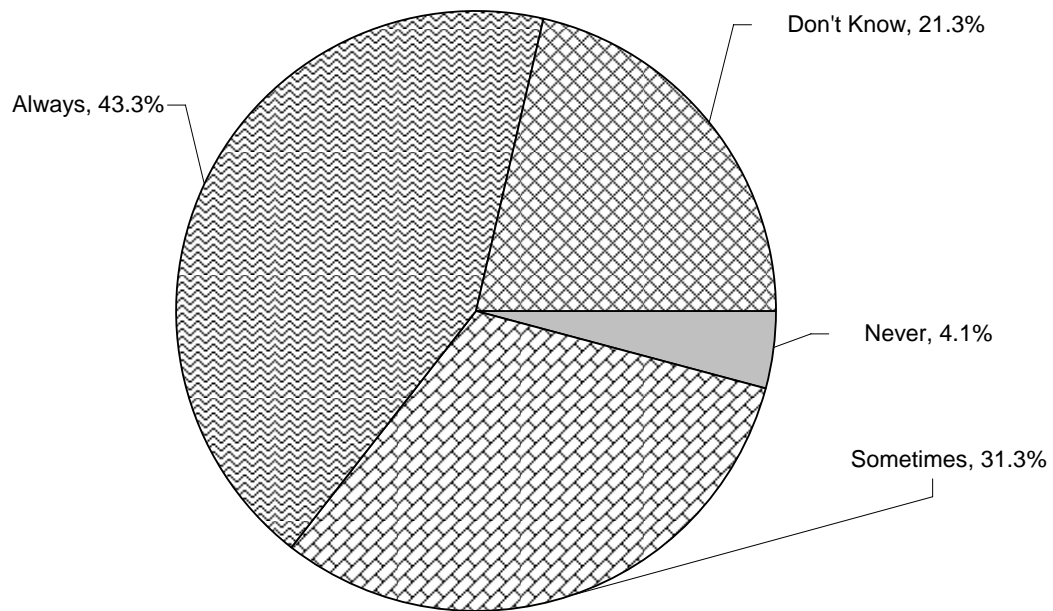
- ☐ Never
☐ Sometimes
☐ Always
☐ Don't know/not sure

Of those answering this question, 99 or 21.5 percent answered "Don't Know". Of those answering other than "Don't Know", 198 or 54.8 percent answered always, while the other 163 or 45.2 percent answered sometimes or never. Fourteen surveys left the question blank.

| 11. Do you feel the community-based services you use are organized and easy to use? | | | |
|--|---------------|---------------------------|---------------------------|
| (Check one answer) | | | |
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total Surveys Returned | 474 | 100.0% | |
| Not Answered/Blank | 14 | 3.0% | |
| Non-Blank Answers Received | 460 | 97.0% | 100.0% |
| Never | 19 | 4.0% | 4.1% |
| Sometimes | 144 | 30.4% | 31.3% |
| Always | 199 | 42.0% | 43.3% |
| Don't Know | 98 | 20.7% | 21.3% |

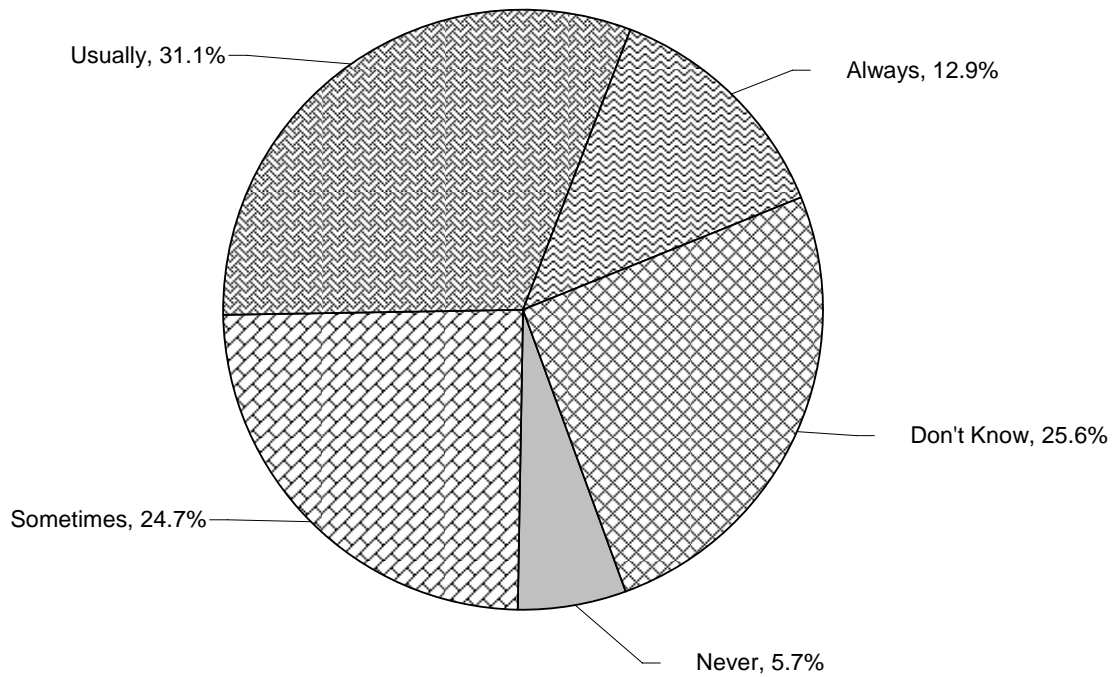
Source: South Dakota Department of Health

Do you feel the community-based services you use are organized and easy to use?
2006



Source: South Dakota Department of Health

Do you feel the community-based services you use are organized and easy to use?
2005



Source: South Dakota Department of Health

12. Do you feel the services your child receives have helped them transition to adult health care, work and independence? (Check one answer)

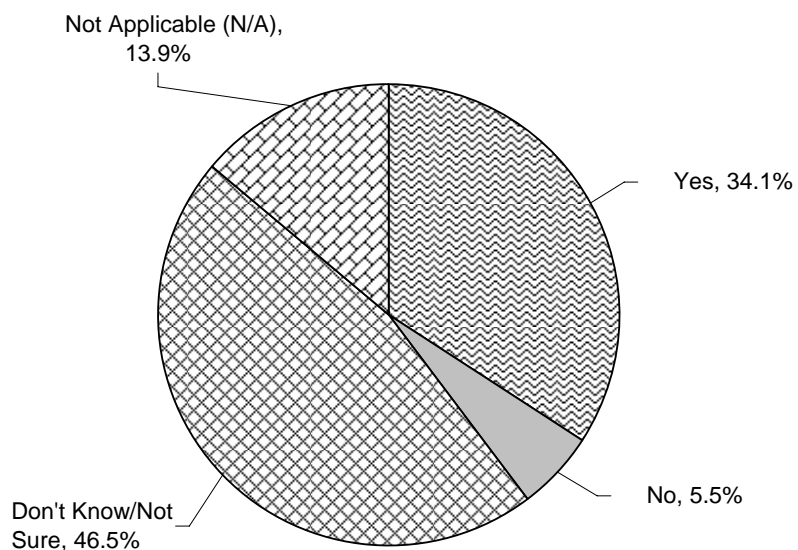
☐ Yes
☐ No
☐ Don't know/not sure

Of the 469 respondents, 218 or 46.5 percent answered don't know/not sure, 160 or 34.1 percent answered yes, 65 or 13.9 percent not applicable (N/A), and 26 or 5.5 percent answered no. Five surveys left the question blank.

| 12. Do you feel the services your child receives have helped them transition to adult health care, work and independence? (Check one answer) | | | |
|---|---------------|---------------------------|---------------------------|
| Survey/Question Response | Number | Percent of Surveys | Percent of Answers |
| Total Surveys Returned | 474 | 100.0% | |
| Not Answered/Blank | 5 | 1.1% | |
| Non-Blank Answers Received | 469 | 98.9% | 100.0% |
| Yes | 160 | 33.8% | 34.1% |
| No | 26 | 5.5% | 5.5% |
| Don't Know/Not Sure | 218 | 46.0% | 46.5% |
| Not Applicable (N/A) | 65 | 13.7% | 13.9% |

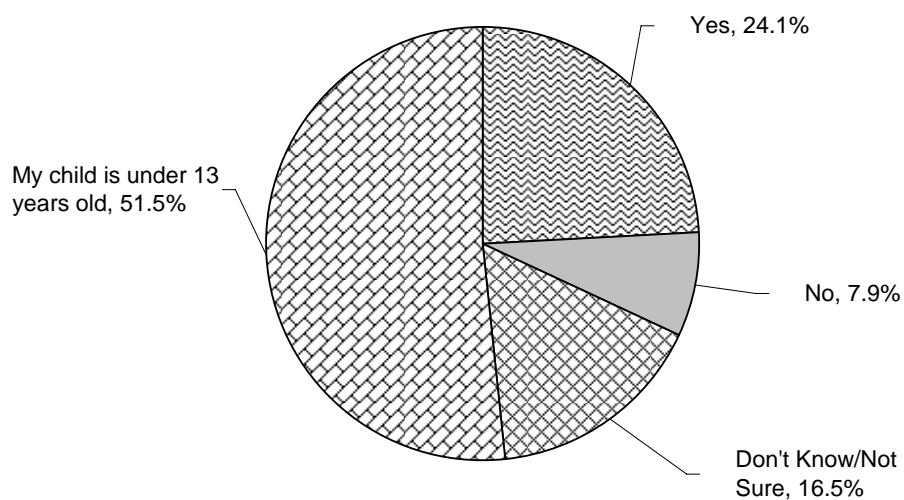
Source: South Dakota Department of Health

**Do you feel the services your child receives have helped them transition to adult health care, work and independence?
2006**



Source: South Dakota Department of Health

**Do you feel the services your child receives have helped them transition to adult health care, work and independence?
2005**



Source: South Dakota Department of Health

Appendix

SD Parent Connection / Children's Special Health Services

2005-2006 PARENT SURVEY

Please complete one survey for each child in your household with a special health care need that has lasted or is expected to last 12 months or longer. Special health care needs are conditions that require more than the usual medical, mental health, or educational services.

If you have more than one child with special health care needs and require additional copies of this survey or have questions about completing this survey call 1-800-738-2301.

1. County where you live: _____.

2. What is the child's age? _____.

3. List your child's condition that requires more than the usual medical care, mental health, or educational services that has lasted or is expected to last 12 months or longer.

4. How do you pay for your child's health care services? (Check all that apply)

- ☐ Privately Purchased Insurance
- ☐ Employer Group Insurance
- ☐ Medicaid/CHIP
- ☐ Indian Health Services
- ☐ Tri-Care (Military Coverage)
- ☐ Out of pocket/Self pay

5a. Do you feel you have adequate health insurance? (Check one answer)

- ☐ Yes
- ☐ No

5b. If no, why? (Check all that apply)

- ☐ High Co-pay or Deductible
- ☐ Rider on the Policy
- ☐ Pre-existing Condition
- ☐ Out of Network Providers
- ☐ Services are Excluded
- ☐ Uninsured

6. Types of medical care/treatment needed?

| Service | Miles from Home | Visits per Year |
|---|--|--|
| Care/Treatment | The number of miles traveled (one way) for each service listed | The number of visits needed annually for each service listed |
| Prescription Drugs (Pharmacy) | | |
| Therapy(physical, occupational, speech) | | |
| Routine lab tests | | |
| Primary care physician visits | | |
| Specialty care physician visits | | |
| Special equipment | | |
| Counseling | | |
| Other (List) _____ | | |

(Over)

7a. As parents, are you satisfied with the involvement you have had with your child's health care team in making decisions about what care is provided to your child? (Check one answer)

☐ Yes
☐ No

7b. If no, why? (Check all that apply)

☐ Do not understand medical terms
☐ Team does not include us
☐ Afraid to ask questions
☐ Didn't know I could help make decisions
☐ Other reasons (List): _____

8. Does your child's primary doctor work with you to identify and access all the medical and non-medical services needed to help your child and family achieve their goals? (Check one answer)

☐ Yes
☐ No
☐ Don't Know/Not Sure

9. How would you rate the communication between your child's primary doctor and other health care providers about your child's care? (Check one answer)

☐ Very Good
☐ Good
☐ Poor
☐ Communication not needed
☐ Don't Know/Not Sure

10. How would you rate the communication between your child's primary doctor and each of the following: (child's) school, early intervention program, child care providers, or vocational rehabilitation program?

| Rating: | School | Early Intervention Program | Child Care Provider | Vocational Rehab Program |
|--------------------------|--------|----------------------------|---------------------|--------------------------|
| Very Good | | | | |
| Good | | | | |
| Poor | | | | |
| Communication not needed | | | | |
| Don't Know/Not Sure | | | | |

11. Do you feel the community-based services you use are organized and easy to use? (Check one answer)

☐ Never
☐ Sometimes
☐ Always
☐ Don't Know/Not Sure

12. Do you feel the services your child receives have helped them transition to adult health care, work and independence? (Check one answer)

☐ Yes
☐ No
☐ Don't Know/Not Sure

Your thoughts are important to us. Thank you for taking the time to complete and return this survey.

After completion return the survey(s) to South Dakota Department of Health, CSHCN Survey, 615 East Fourth Street, Pierre, South Dakota 57501 on or before February 20, 2006.

SD Parent Connection / Children's Special Health Services

2004-2005 PARENT SURVEY

Please complete each question for each child in your household with a special health care condition and return it to South Dakota Department of Health, CSHCN Survey, 600 East Capitol Avenue, Pierre, South Dakota 57501 on or before November 26, 2004. (Use enclosed self addressed postpaid envelope) This survey will accommodate up to three children, additional copies may be obtained at www.state.sd.us/doh/ or by calling 1-800-738-2301.

1. County of Residence _____?

2. What are the children's ages:

Child 1 _____ Child 2 _____ Child 3 _____

3. What health care conditions does your child have? (Check all that apply)

Child 1 Child 2 Child 3

_____ Asthma
 _____ Diabetes
 _____ Cerebral Palsy
 _____ Heart Condition
 _____ Epilepsy or seizures
 _____ ADD/ADHD
 _____ Autism
 _____ Hearing Impairment
 _____ Learning Disability
 _____ Visual Impairment
 _____ Emotional Health

Other conditions: Child1 _____ Child2 _____ Child3 _____

4. How do you pay for your child's health care services? (Check all that apply)

Child 1 Child 2 Child 3

_____ Privately Purchased Insurance
 _____ Employer Group Insurance
 _____ Medicaid/CHIP
 _____ Indian Health Services
 _____ Tri-Care (Military Coverage)
 _____ Out of pocket/Self pay

5a. Do you feel you have adequate health insurance?

Child 1 Child 2 Child 3

_____ Yes
 _____ No

5b. If No Why? (Check all that apply)

Child 1 Child 2 Child 3

_____ High Co-pay or Deductible
 _____ Rider on the Policy
 _____ Pre-existing Condition
 _____ Out of Network Providers
 _____ Services are Excluded
 _____ Uninsured

6. Types of medical care/treatment needed?

| Service | Miles from Home | | | Visits per Year | | |
|----------------------------------|-----------------|---------|---------|-----------------|---------|---------|
| Care/treatment | Child 1 | Child 2 | Child 3 | Child 1 | Child 2 | Child 3 |
| Prescription Drugs (Pharmacy) | | | | | | |
| Therapies | | | | | | |
| Frequent lab tests | | | | | | |
| Primary care physician visits | | | | | | |
| Specialist care physician visits | | | | | | |
| Special equipment | | | | | | |
| Surgery | | | | | | |
| Other (List) | | | | | | |

(Over)

7a. As parents, have you been satisfied with the involvement you have had with your child's health care team in making decisions about what care is provided to your child?

Child 1 Child 2 Child 3

_____ Yes

_____ No

7b. If No Why? (Check all that apply)

Child 1 Child 2 Child 3

_____ Do not understand medical terms

_____ Not included by provider(s)

_____ Afraid to ask questions

_____ Didn't know I could help make decisions

Other reasons: Child 1 _____ Child 2 _____ Child 3 _____

8. Does your child's primary doctor work with you to identify and access all the medical and non-medical services needed to help your child and family achieve their goals?

Child 1 Child 2 Child 3

_____ Yes

_____ No

_____ Don't Know/Not Sure

9. How well do you think your child's primary doctor and other health care providers communicate with each other about your child's care?

Child 1 Child 2 Child 3

_____ Excellent

_____ Very Good

_____ Good

_____ Fair

_____ Poor

_____ Communication not Needed

_____ Don't Know

10. How well do you think your child's primary doctor communicates with each of the following: (his/her) school, early intervention program, child care providers, or vocational rehabilitation program?

| Rating: | School | | | Early Intervention Program | | | Child Care Provider | | | Vocational Rehab Program | | |
|--------------------------|--------|---|---|----------------------------|---|---|---------------------|---|---|--------------------------|---|---|
| | Child | | | Child | | | Child | | | Child | | |
| | 1 | 2 | 3 | 1 | 2 | 3 | 1 | 2 | 3 | 1 | 2 | 3 |
| Excellent | | | | | | | | | | | | |
| Very Good | | | | | | | | | | | | |
| Good | | | | | | | | | | | | |
| Fair | | | | | | | | | | | | |
| Poor | | | | | | | | | | | | |
| Communication not Needed | | | | | | | | | | | | |
| Don't Know | | | | | | | | | | | | |

11. Are you satisfied with services available to help your child transition to adult life?

Child 1 Child 2 Child 3

_____ Yes

_____ No

_____ Don't Know/Not Sure

_____ My child is under 13 years old

12. Are the community-based services organized in a way that makes them easy to use? Would you say this is true never, sometimes, usually or always?

Child 1 Child 2 Child 3

_____ Never

_____ Sometimes

_____ Usually

_____ Always

_____ Don't Know

Thank you for completing and returning this survey.